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Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV

WHO/UNICEF Global Consultation



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Blantyre, Malawi



**World Health
Organization**

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Acronyms

AIDS	acquired immunodeficiency syndrome
ART	antiretroviral treatment
ARV	antiretroviral
FBO	faith based organization
FP	family planning
GYCA	Global Youth Coalition on HIV/AIDS
HIV	human immunodeficiency virus
IAC	international AIDS Conference
IDU	injecting drug use
IEC	information education and communication
IMAI	Integrated Management of Adolescent and Adult Illness
IGO	international governmental organization
IPPF	International Planned Parenthood Federation
IPT	intermittent preventive treatment
NGO	nongovernmental organization
OI	opportunistic infection
ORS	oral rehydration salts
PCP	Pneumocystis carini pneumonia
PEP	post-exposure prophylaxis
PEPFAR	The US President's Emergency Plan for AIDS Relief
PMTCT	prevention of mother-to-child transmission
SRH	sexual and reproductive health
STI	sexually transmitted infection
TB	tuberculosis
UN	United Nations
UNICEF	United Nations Children's Fund
VCT	voluntary counselling and testing
VIPP	Visualization in Participatory Programmes
WHO	World Health Organization
YPLHIV	young people living with HIV

Executive summary

Over 5 million¹ young people are living with HIV, although the vast majority of them do not know that they are infected. With increasing access to HIV testing, more and more young people are likely to discover that they are infected. While some of them will require antiretroviral (ARV) treatment and/or treatment for opportunistic infections (OIs), many will not. Those young people who do not require treatment will, however, require care, support and prevention, and preparation for when they do require treatment. In addition to those adolescents who become infected with HIV during adolescence, with increasing access to ARVs more and more of the children who become infected through vertical transmission will survive into adolescence, and will require ongoing treatment, care, support and prevention during this new and often challenging phase of their lives. The health sector will need to be clear about its role in addressing the specific, complex and diverse needs of adolescents and youth living with HIV.

Recognizing the need to better understand and respond to the health needs of young people living with HIV and AIDS, the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) convened a global consultation on *Strengthening the Health Sector Response to Care, Support, Treatment, and Prevention for Young People living with HIV/AIDS* in Blantyre, Malawi, from 13 to 17 November 2006. The meeting was hosted by UNICEF Malawi, and included more than 45 participants from 18 countries, including young people, a number of them living with HIV; health workers, from a range of professional backgrounds, involved in providing HIV/AIDS treatment, care, support and prevention for young people living with HIV (YPLHIV); and representatives from UN agencies and international and national nongovernmental organizations (NGOs) that are working with young people living with HIV and supporting programmes to meet their needs.

The overarching objective of the consultation was to review and synthesize the experiences of young people living with HIV and health workers responsible for providing services for them, including the identification of gaps and obstacles in the provision and use of services, in order to offer practical recommendations on how to improve the health sector response. Eight priority challenges were identified to which the health sector should respond:

- lack of accurate, relevant, appropriate and non-judgemental information targeting young people;
- lack of services, as a result of multiple barriers to provision, access and use, including scarcity of adolescent-friendly health workers;
- consent and confidentiality;
- lack of psychosocial support;
- problems with adherence;
- difficulties with disclosure;
- stigma, discrimination and isolation; and
- transitions of care (from paediatric to adolescent, and from adolescent to adult).

¹ The statistics have been updated since the Malawi consultation, and the new updated statistics are presented in this report.

The health sector needs to provide young people living with HIV with a range of services, including developmentally appropriate information about HIV and AIDS; physical and psychosocial care and treatment for HIV and AIDS; mental health and sexual and reproductive health services; and linkages and referral between services in the health sector, and with services provided by other sectors. In addition, it is important to bear in mind the different needs of young people infected with HIV during adolescence, and those young people who were infected during the perinatal period. Based on these priorities, the consultation identified the following issues requiring further development:

- standards for health services for YPLHIV;
- minimum and minimum-plus treatment/care packages for YPLHIV;
- approaches to the provision of psychosocial support for YPLHIV;
- training and orientation of health care workers to provide information and services for YPLHIV;
- training and supporting young people to contribute to health sector activities for YPLHIV; and
- linking with other sectors in order to strengthen the health sector response to care, support, treatment and prevention for YPLHIV.

The consultation highlighted the considerable need for better data on different groups of young people living with HIV, in terms of current and future needs for treatment and care, and for additional research focused on identifying and responding to their specific needs. The meeting concluded with the formulation of action plans relating to the priority challenges facing the health sector, including tasks to be accomplished in the next 6 and 24 months, and responsibilities for achieving them.

1. Background and rationale

The Declaration of Commitment on HIV/AIDS, endorsed by the UN General Assembly in 2001, “...embraced equitable access to care and treatment as a fundamental component of a comprehensive and effective global HIV response.”¹ As a step towards universal access to HIV prevention and treatment for all who need it, WHO launched the “3 by 5” initiative on World AIDS Day in 2003, which aimed to provide treatment for three million people living with HIV in low- and middle-income countries by 2005. At the same time, the advent of the Global Fund to Fight AIDS, Tuberculosis and Malaria and other funding initiatives have greatly increased the level of resources available for treatment in countries. These efforts have galvanized global support to expand access to treatment and have “...demonstrated the feasibility of delivering HIV treatment in even the most resource-limited settings, and confirmed that the extraordinary declines in AIDS-related illness and death seen in high-income countries can be achieved in low- and middle-income countries as well.”²

As of 2007, more than 30 million people were living with HIV, 5.4 million of whom were young people 15-24 years of age.³ These young people comprise both those infected during adolescence and those infected through mother-to-child transmission who survive into adolescence. As a result of the life-prolonging effects of antiretroviral therapy, the number of young people living with HIV due to infection during the perinatal period is expected to rise. At the same time, efforts to facilitate people’s access to HIV testing are likely to increase the number of young people who know that they are infected as a result of transmission during adolescence.

With the focus on the benefits of ART, it is easy to forget that treatment is only one aspect of comprehensive care for young people living with HIV. The majority of young people who become infected with HIV during adolescence are unlikely to require ARVs because of the delay between infection and the development of symptoms that require treatment. However, during this period they *will* require care, support and prevention, and this is an important time for treatment preparedness.

Many sectors will need to be involved in national responses to meeting the needs and rights of young people living with HIV. However, the health sector will need to play a central role, and in order for it to do this it will be important to understand the specific needs of young people living with HIV, including the needs of different groups of young people defined by characteristics such as age, sex, marital status, parental support, sexual orientation, socioeconomic status and context, and different epidemic scenarios.

As a contribution to improving and expanding the role of the health sector, WHO and UNICEF organized a global consultation on *Strengthening the Health Sector Response to Care, Support, Treatment, and Prevention for Young People Living with HIV/AIDS*. The consultation had several objectives:

- to review and synthesize the needs for care, support, treatment and prevention for adolescents and youth living with HIV, in order to make a compelling case for action;

¹ See UNAIDS (2006).

² Ibid.

³ The Malawi consultation focused on young people, 10-24 years, although particular attention was paid to adolescents, 10-19 years, with disaggregation by age and sex, when the data were available, and attention to time and mode of infection.

- to define priority elements of care, support, treatment and prevention for YPLHIV;
- to share experiences about interventions for meeting young people's needs, including a focus on increasing access and adherence to treatment and care;
- to review available programme support materials and strategies in order to be clear about what is available, and what needs to be developed; and
- to develop an action plan for the development and implementation of priority interventions.

Before the workshop commenced, several desired outputs were identified:

- peer-review and finalization of the background papers¹ prepared for the consultation;
- a report from the consultation synthesizing the discussions and recommendations; and
- a network of individuals and organizations committed to advocating for and accelerating health sector action to provide care, support, treatment and prevention for YPLHIV.

Despite the growing number of young people living with HIV, their treatment, care, support and prevention needs remain missing from the global agenda. Young people have different needs from small children and adults, and require different approaches to meeting these needs. The Malawi consultation will make a contribution both to understanding the diverse and unique care, support, treatment and prevention concerns of young people living with HIV, and also to achieving recent commitments to universal access, and to existing global goals and targets endorsed during the UN General Assembly Special Sessions on AIDS and Children, New York 2001, and the subsequent high-level meeting held in New York, 2006.

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